



Payton's story

"As a mother, you do everything you can for your child," explained Niki Ferguson. "I didn't want regrets later; I wanted to do everything I possibly could to make everything OK."

Niki was referring to Payton, her second son. Niki, her husband Ryan, and four-year old son Ethan learned at a routine 20-week ultrasound that there were complications with Niki's pregnancy. An amniocentesis confirmed their unborn son, Payton, had Trisomy 13 and 17, a genetic disorder associated with the presence of extra material from chromosomes. Payton had something wrong with his brain, his heart and his kidneys.

"Once we had confirmation of Payton's disorder, the doctor didn't get into a lot because he wanted me to have an abortion. I told him that wasn't an option. Unless it became life threatening to me, I was going through with the pregnancy," explained Niki. "Basically, no one thought Payton would make it through the pregnancy let alone labor."

It was at her dental office when Niki first learned of Mercy's pediatric home care program. "The wife of the dentist that I work for, passed me an article on Mercy's pediatric program. I read the story. We talked with my obstetrician, the pediatrician and set up Mercy's pediatric home program," explained Niki.

Since 1998, Mercy's pediatric home care has served more than a thousand critically ill children. It is one of the only programs in our area that solely focuses on delivering home healthcare, palliative care and hospice care to children.

After 5 months of pregnancy, Niki developed extra fluid around the baby and went weekly to her obstetrician. "Payton wasn't digesting the amniotic fluid. They thought he would be still born. For Payton to survive 37 weeks was a miracle," said Niki.

Payton was born on August 8, 2008 and weighed 5 lbs even. "Other than his extra digits -six fingers and six toes, he looked like a normal kid. You could see a difference in his eyes. Payton didn't have any pupils, they were solid blue," explained Ryan.



The Ferguson family pictured with their nurse, share their story of Payton and how precious his life was. Pictured from left are Amanda Manning, Mercy pediatric nurse, Ethan, Payton (in the center photo), Ryan and Niki Ferguson.

An ultrasound of Payton revealed his brain didn't have the amount of fluid as they originally suspected and the chambers of his heart weren't flipped. Payton's heart had multiple holes, he was jaundice because of his liver and kidney issues, and had a feeding tube.

"We didn't realize at first that Payton had a cleft palate. He couldn't take bottles. Every time he did, it would choke him and he would turn blue. We had to learn how to use a feeding tube," said Niki.

After six days in the hospital, Payton was released to go home. Amanda Manning, Mercy's pediatric nurse was waiting.

"Amanda stepped in and was gracious through the whole process. We couldn't have asked for a better person to be with our family during that time. It was as if we had known her for 15 to 20 years. She shared our emotions and our thoughts," explained Ryan.

The Fergusons valued home care. "No matter what time Payton had, we didn't want him spending it in a hospital. We wanted him around family and friends who could love him and show him attention that anybody else would want to give their own kid. Our goal was making him happy with what little time we had," explained Ryan.

Near the end of Payton's life, there were some difficult times but the Mercy

nurses proved their vocation wasn't just a job.

"We had a really bad weekend. Payton turned colors and gasped for air. He did this 15 or twenty times. We've dealt with different doctors and have family in the medical field. For Amanda and Kristen to help during that time, and be able to comfort and to console us was extraordinary. We watched their emotions. They cried right along with us. It showed us it wasn't just about a job for them, it was personal. It meant so much. It will never go away from my wife's or my mind or anybody else that was here during that time," recounted Ryan.

"God was on our side to give us time, whether it was a minute or a day. As it turned out it was almost a month. We appreciated every moment. No matter what you go through it is worth it. Just to experience a part of their life. We don't regret anything. Just to be able to see Payton, hold him and know we did everything we could," explained the Fergusons.

Living through Trisomy 13 is very painful and yet very joyful. It may be best explained why parents like the Fergusons choose their path, in a quote taken from the living with Trisomy 13 website – "God's gifts are never what we expect. The trick is not to be confused by the wrapping paper, but to be sure to open the box."

